



A Publication of the Hawai'i Department of Health Genetics Program

Hawai'i Birth Defects Administrator Receives National Award

Ruth D. Merz, MS has been the administrator of the Hawai'i Birth Defects Program for the past 15 years. Ruth has also been very active in the National Birth Defects Professional Association, including: serving on the Executive Committee, heading the annual elections, chairing committees, and currently serving as the Member-At-Large in 2004.

On January 23, 2004, Ruth was presented with the National Birth Defects Prevention Network, Inc. **President's Award for 2003**. This award has only been presented to deserving individuals three times in the last seven years. It was quite an honor for a person from such a small state to receive this national recognition for her many contributions at the national level.

With birth defects being the number one cause of infant mortality in Hawai'i, the Hawai'i Birth Defects Program (HBDP) was established in 1988 to be a reliable and timely information source for ascertaining the number of children statewide diagnosed with congenital anomalies. With over 17,500 cases in its database, major activities of the HBDP include responding to inquiries for data and information from the community, presentations to diverse audiences, research activities, numerous publications including the publication of the annual 135 page Hawai'i birth defects data report. The HBDP has served as the pilot site for the national Gulf War Syndrome project and has participated in several local, regional, and national research study activities. Nationally, the HBDP has been fortunate to be one of few states to receive an "A" grade from both the Pew Charitable Trust, and Trust for America's Health for all its accomplishments.

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Coordinator's Corner

My program staff and I want to congratulate Ruth Merz on her national award. She has worked tirelessly to develop and improve the Hawai'i Birth Defects Program. It certainly is a well deserved honor.

The first quarter of this year has been very busy for the Genetics Program. We've been writing grant applications, teaching, developing resources, doing research, and providing clinical services. Please check our website for information about all our activities.

Remember, if you have comments (good or bad) or questions about GeneNews, our website or any of our activities, please contact me at sylvia@hawaiigenetics.org or 733-9063. I look forward to hearing from you.

Sylvia M. Au, M.S., C.G.C.
State Genetics Coordinator



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Genetics Education Resource Kits



As part of our involvement with educational activities across the state, the Hawai'i Genetics Program is developing a "Genetics Education Resource Kit" for Hawai'i's science teachers. The kit will include materials and resources to help our state's science educators teach the genetics components of the curriculum. Focus groups are being held to help develop resource kit materials. The teachers attending these groups have provided valuable insights regarding the genetics resources that would be the most useful in science classrooms. Among other topics, we have discussed the lesson plans and resources currently used, genetics labs & activities, internet resources, ethical issues surrounding genetics, and the

potential of a traveling laboratory. We have been pleased with the support and enthusiasm shown by the focus group participants on O'ahu, Maui and the Big Island. We welcome any input regarding the development of the "Genetics Education Resource Kit" and encourage you to contact Kirsty McWalter with any comments or questions.

HaSTA Conference



The Hawai'i Genetics Program is pleased to announce our involvement in the HaSTA (Hawaii Science Teachers' Association) Conference this spring. The conference took place on Saturday, May 1st at the new Science and Technology building at Mid Pacific Institute. The Hawai'i Genetics Program busily planned two breakout sessions for the conference. One involved resources currently available to teachers teaching genetics, and the other looked at ethical and legal genetics issues to discuss within the classroom. We enjoyed sharing new genetics developments and teaching ideas with Hawai'i's science teachers during these sessions. If you have thoughts regarding the breakout sessions, or other comments or questions, please contact Kirsty McWalter at

kirsty@hawaiiigenetics.org



2004 Genetics Conference for Allied Health Professionals

Due to popular demand, we will be holding a Genetics Conference for Allied Health Professionals this coming fall.

Topics include:

- ✍ Tools to Triage Your Patients for Genetic Evaluation
- ✍ Update on Genetics of Common Chronic Diseases
- ✍ New Treatments for the Prevention and Management of Genetic Disease
- ✍ Discussion on the Current Ethical, Legal and Social Issues Surrounding Genetic Screening and Testing

Conference brochures will be mailed out this Summer, and will be available on our website this summer. Register early since seating will be limited!



EXPO 2004

ANAHEIM, CA

***On February 7th
and 8th, the
Hawai'i Genetics
Program attended
the annual Yeah
Baby Expo in
Anaheim,
California.
Boasting an
average annual
attendance of
50,000, the Yeah
Baby Expo included
over 200 exhibitors,
several celebrity
guests and
musicians, prizes,
games, and much
more!***



While at the Yeah Baby Expo, we took the opportunity to survey the California attendees about a new newborn metabolic screening (NBMS) brochure. The information we collected was then compared to similar data gathered at the May 2003 New Baby Expo in Hawai'i. A total of 2,042 Yeah Baby Expo attendees completed our surveys.



Although the respondents preferred pastel colors (46.7%) for the brochure, primary colors were a close second with 42.1% of the votes. The most popular title was "The Newborn Screening Blood Test for Your Baby's Health" (38.7%), and 80.8% wanted the brochure to have a question and answer format. A picture of a baby's hand holding the finger of an adult's hand was the favorite image of almost half of the female attendees (43.9%). However, a more traditional picture of a mother holding her baby was preferred by 30.3% of the men. In addition, respondents usually liked pictures of people of the same or similar ethnic background as themselves.

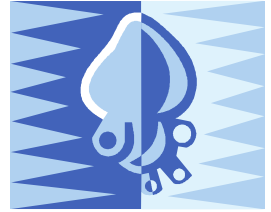
The majority of respondents believed that the brochure should be easy to understand (77.2%), be informative (51.4%), be simple (43.0%), and provide contact information (39.8%). A smaller number wanted the brochure to contain many pictures (10.8%) and be colorful (7.7%).



Most of the results and trends uncovered by the Yeah Baby Expo surveys were very similar to the results from surveys completed at the Hawai'i New Baby Expo. Based on the comments and suggestions from both the California and Hawai'i Baby Expo attendees, we are developing a colorful, simple and informative NBMS brochure for parents to read and learn from! In May, these brochures will be reviewed by moms and dads at Hawai'i WIC clinics before being released to the general public. We will let everyone know as soon as these brochures are ready for distribution!



**For more information,
please go
www.hawaiigenetics.org**



Gene Mutations Cause Heart Patients to 'Ignore' Stress Signals Which May Lead To Heart Failure



Whether or not your heart can respond to "alarm signals" may determine your risk for heart failure.

In an April 2004 *Nature Genetics* article, Mayo clinic researchers report the discovery of gene mutations that make a person's heart fail to recognize stressful signals from the body. As a result, the heart cannot properly adjust and manage the stress that makes the heart more vulnerable to damage. Historically, genetic research into heart failure has concentrated on looking for defects in the proteins responsible for heart pumping. This is the first time that heart failure has been viewed as a communication failure or signaling problem in the stress management of the heart cells. This discovery is important since so little is known about the method the heart uses to respond to body stresses. Understanding the molecular basis of how the heart responds to stress may lead to new treatments to prevent heart failure.

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